



Huntington's Disease  
Society of America

*Strategic Plan*  
*2017-2021*





## Table of Contents

Acknowledgement.....	3
Strategic Planning Committee Roster.....	4
Introduction.....	5
Who We Are: The Fundamentals.....	7
Plan Overview.....	10
HDSA Strategic Plan 2017-2021.....	15
Glossary of Terms.....	38
HDSA Strategic Plan 2012-17: Outcomes Report.....	41

## ACKNOWLEDGEMENT

We would like to thank the Huntington's disease community, who actively shared their personal experiences on life with HD to shape the Huntington's Disease Society of America's new Strategic Plan.

At regional meetings with leaders of HDSA Chapters and Affiliates, in sessions at the HDSA Annual Convention, and with online surveys, thousands of individuals contributed their vision for the organization and provided great detail about what "improving life with HD" means to them. This feedback directly informed HDSA's plans for the next five years as presented in this document.

HDSA remains an organization of families for families, and we are deeply grateful for their passionate participation in making sure that HDSA accomplishes the help and hope that our families need.

## Strategic Planning Committee Members

Arik Johnson, PsyD  
*Committee Chair*  
Chair, HDSA Board of Trustees  
Los Angeles, CA

Claudia R. Adkison, JD  
Atlanta, GA

Jang-Ho Cha, MD, PhD  
Cambridge, MA

Hugh de Loayza  
Sausalito, CA

Steven V. Seekins  
Burbank, CA

Arvind Sreedharan  
Libertyville, IL

Daniel Vandivort  
Charleston, SC

Louise A. Vetter  
New York, NY

### INTRODUCTION

In 2012, the Huntington's Disease Society of America released its first Strategic Plan. Developed by the HDSA Board of Trustees with the input of the HD community and scientific and clinical advisors, the five-year plan was a new approach and bold commitment to the fight against Huntington's disease (HD) for the organization. It provided specific goals, strategies and tactics for what the Society would be accomplishing, as well as when and how.

The Plan clarified the Society's mission – *to improve the lives of people with HD and their families* – and it articulated an aspirational vision – *a world free of HD* – that inspires every member of the HD community. Additionally, it answered key questions about HDSA's purpose. Long-debated topics such as whether to continue funding HD research, what types of community-based services to provide and the importance of organizational growth were addressed, and a clear course was charted which put HD families at the heart of every decision.

Having a Strategic Plan for HDSA meant a deliberate shift from simply "hoping" for better care and a cure to planning for it. Measureable goals were established that challenged every aspect of the organization's mission work and business operations.

The launch of the Plan heralded a new dawn of transparency and communication for HDSA. Community input was actively sought, and drafts of the plan were widely circulated for feedback and debate. Vital conversations about fundraising and financial management took place throughout the organization to ensure that the integrity and sustainability of HDSA's mission work were front and center in the expansion of the advocacy, care, education and research to which HDSA was committed.

The work that resulted from the Plan has been inspiring. Within months of its launch, HDSA Chapters and Affiliates nationwide were analyzing the document and identifying components that they wanted to work on in their own communities. This ripple effect of implementation jump-started the plan's achievement and paved the way for the accomplishments that would take place during the following five years.

Long enough to see impact but short enough to allow for specificity, the five year plan guided HDSA through a period of growth and impact unique to the organization. Since 2012, we have grown our resources nearly 33 percent – from \$7.6 million to \$10.1 – which has led to the strengthening of our entire mission portfolio.

From the new HDSA HD Human Biology Project research initiative to the expansion of the HDSA Centers of Excellence program, we have a comprehensive portfolio of services to support families at every stage of the disease, as well as a vital and unique science program. Our advocacy work has mobilized an army of passionate leaders unparalleled in rare disease, and our community services form a broad net that has fewer gaps with every passing day.

This new plan for the period of 2017-2021 celebrates these accomplishments and challenges us to be even more specific and accountable in our outcomes as we move forward. The seven strategic goals have matured to be more specific in their family-focused outcomes.

The strategies are more deliberate, pushing HDSA to address persistent unmet needs, such as long term care and youth support. The tactics require the unity and collaboration that is our strength and will ultimately bring therapeutic solutions.

Building on HDSA's recent as well as long-established successes, the HDSA Strategic Plan 2017-2021 charts a clear path for continuing to improve the lives of families affected by HD, so that as long as there are families affected by Huntington's disease, HDSA will be a trusted resource, partner, advocate and pioneer for them.

## WHO WE ARE: THE FUNDAMENTALS

**Our Vision:** *A world free of Huntington's disease.*

A vision statement is the broadest, most aspirational dream of an organization. It functions like a “north star” to guide and inspire the future directions of what HDSA hopes to achieve. Our vision statement represents our overarching commitment to the ultimate goal of eradicating Huntington's disease.

When stated before the mission, it should be read in a manner that directly ties it to our mission as follows: *The vision of the Huntington's Disease Society of America is a world free of Huntington's disease. Until that time, our mission is to improve the lives of people with Huntington's disease and their families.*

**Our Mission:** *To improve the lives of people with Huntington's disease and their families.*

The mission of the Society is a concise, active statement of the Society's work. In comparison to the vision statement, it describes the Society's purpose and who will benefit from it.

It should be noted that the mission statement is separate from the organizational purposes described in the organization's bylaws. Those statements provide historical reference and additional detail about how HDSA accomplishes its work and are as follows:

- To promote and support research and medical efforts to eradicate HD.
- To assist people and families affected by HD to cope with the problems presented by the disease.
- To educate the public and health professionals about HD.

They remain in the bylaws without edit, but we no longer reference a three-part mission. The mission is one simple statement: *To improve the lives of people with Huntington's disease and their families.*

### Our Core Values

While the Vision and Mission describe the organization's guiding principles, the Core Values form the foundation on which we perform work and conduct ourselves. At HDSA, we are committed to these shared values:

- *Hopeful* – We conduct our work in all areas in a manner that inspires hope. Our vision epitomizes this hope, and all work is done in a way that is always forward-looking.
- *Dedicated* – We are dedicated to serving people with Huntington's disease and their families and supporting research to drive a cure. We care intensely about those we represent and serve. We celebrate our wins and inspire dedication from those who work with us.
- *Family-Focused* – In direct correlation to the nature of Huntington's disease, we are a family-based and family-focused organization. Our structure, programs and decisions reflect a commitment to a family-centric model. We value the work of our volunteers who represent our families and who function as a family. All members of our team – staff, volunteers, Chapter and Affiliate Board leaders, donors, clinicians, care providers, scientists, and sponsors – are important members of the HDSA family.
- *Compassionate* – We are a sympathetic and empathetic network of individuals and families. We know that excellence in care comes from sincere compassion, and we strive to reflect this compassion in our community activities and relationships.
- *Mission-driven* – It is important to the Society that all work of the organization is driven by a consistent and strategic focus on accomplishing our mission. Our policies, positions and programs are rooted in credible and well-validated science, and we ensure that our decision-making and leadership align with the mission statement. Our drive to grow is so that we can expand our resources, support and impact for more families.
- *Collaborative & Accessible* – We are a 'hub' or central 'portal' for the HD Community, its families and all stakeholders. We partner and collaborate with others who serve the HD community, and we listen and act to provide support to our community, or direct them to another who can.
- *Stewardship* – As stewards, our volunteers and staff are accountable to our donors. Decisions about how to invest time, people and money to accomplish our mission are based on the highest impact of return on investment to our mission. We employ practices that maximize efficiency and effectiveness, and we evaluate initiatives in light of our mission-driven objectives.
- *Accountable* – Stewardship is reinforced by our accountability. Accountability motivates our volunteers and staff to manage our resources effectively and take actions in the best interest of the people we represent and serve. We are transparent, with mutual responsibility at all levels of the organization.



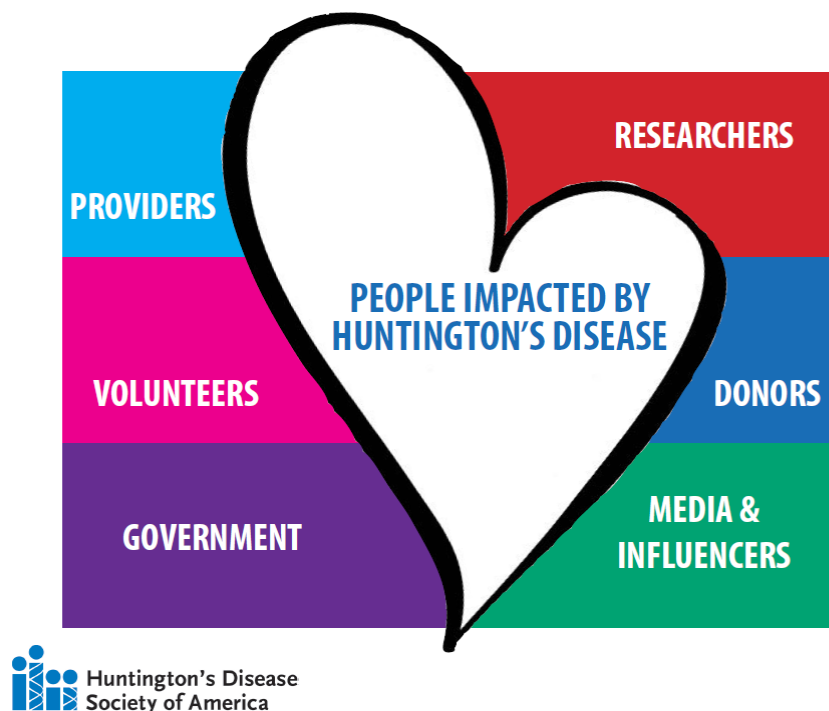
## Our Community

In the truest sense, the heart of our community is those impacted by Huntington's disease, which includes individuals symptomatic with the disease, those at-risk, and the families and friends who are caring for people with HD. From the youngest affected by juvenile-onset HD to the grandparents who have lost spouses, children and care for grandchildren who carry its burden, we are driven to serve *everyone* who is affected by HD.

Many audiences contribute to the Society's ability to care for and support a cure for HD families, and they constitute our secondary community. These include:

- *Providers* – Care providers, like clinicians, mental health professionals, genetic counselors and social workers, who provide medical attention.
- *Researchers* – Anyone who is conducting research that will improve the understanding of HD and assist in the scientific development of treatments and a cure.
- *Volunteers* – Everyone who gives of their time or expertise to support the mission of HDSA.
- *Donors* – Financial contributors to HDSA.
- *Government* – Any member of local, state or federal government. This includes elected officials and members of regulatory agencies, like the Food and Drug Administration and Social Security Administration.
- *Media & Influencers* - Members of the media and thought leaders in the realm of public opinion who are vital in raising awareness of HD.

The backdrop for these categories of audiences is the general public with whom we seek to raise general awareness of Huntington's disease and therefore influence public understanding of the needs of our HD families.



## PLAN OVERVIEW

The Strategic Plan is organized around Seven Goals which are the key drivers of HDSA's service and organizational impact. These Seven Goals are the essential areas of our work which, in equal measure, are imperative to HDSA's ability to accomplish its mission.

For each Goal, strategies are identified to reach the stated aim. Specific objectives for each strategy articulate the plans for accomplishment.

### Goal I: Enhance and Deliver Best Practices in HD Family Care.

HDSA is committed to ensuring that all HD affected families have access to the highest quality of knowledgeable and compassionate care. By expanding geographic reach, increasing access to trained personnel and embracing new technology, we are focused on enhancing the care network nationwide and fostering a model of care that is patient-focused and family-informed.

Additionally, best practices in HD family care must span the entire progression of the disease, as well as its impact throughout generations. From support for the youngest members of the community to care options for those in its final stages, we look across the entire family journey with a firm commitment to improving the quality of life for HD families nationwide.

To accomplish this Goal, five core strategies have been identified:

1. Expand access to HD-experienced clinical care.
2. Enhance social services and support resources.
3. Improve access to long-term care facilities skilled in HD.
4. Increase access to counseling on key HD-related decisions, including genetic counseling and preimplantation genetic diagnosis in vitro fertilization (PGD IVF).
5. Grow network of and resources for HD specialized ancillary services, including occupational therapists, physical therapists, speech language pathologists, and nutritionists.

The objectives which align with these strategies include the continued development of the HDSA Center of Excellence program, expansion of age-appropriate support available to our youth, launch of a new online curriculum and learning practices for ancillary care providers, and the implementation of best practices for HD care in long-term care facilities. Additionally we seek to complement these resources with strong educational tools on genetic testing, the disability process, healthcare planning and the potential for genetic and social discrimination.

### Goal II: Advance HD Research.

We know that the shared hope of the HD community is that care for Huntington's disease will be better for future generations than it is today. To achieve this, HDSA is committed to advancing Huntington's disease research. Our scientific efforts complement the work of the global HD scientific community with deliberate focus on answering questions related to the human biology of HD and building the careers of young investigators.

The four strategies in support of this aim are:

1. Ensure a pipeline of new HD researchers.
2. Strengthen and build partnerships with key research collaborators (i.e. CHDI, European Huntington Disease Network (EHDN), and the Huntington's Study Group (HSG)).
3. Fuel clinical research by ensuring active engagement in clinical studies.
4. Educate the community about the importance and impact of HD research.

In addition to directly supporting research through HDSA awards, such as the Human Biology Project, Berman/Topper Career Development Award and Donald A. King Fellowships, we are committed to educating our community about scientific news and the role of families in advancing all areas of HD science. Researchers and families working together will bring treatments forward, and HDSA will be a vital connector to breakthroughs.

### Goal III: Remove barriers to quality care.

Quality care must be accessible to the families affected by HD who so desperately need it. As a result, the removal of all barriers to this care – be they physical, logistical or psychological - is a critical goal of the Society. To address these issues we advocate for public policy change, cultivate a robust referral network of HD experienced support and care providers, educate clinicians on HD, and provide programs directly to families to help them navigate the care services that are available to them.

Our work must be consistent across the entire family experience so that no matter where an individual is in the fight against Huntington's disease – at-risk, going through testing, newly diagnosed, applying for disability, entering long-term care, or caring for a loved one in any of these stages – there is a community team of supporters and an abundance of resources to help them navigate the best in care.

Three strategies to accomplish this Goal were identified. They are:

1. Pass legislation that directly improves the quality of life for HD families.
2. Expand HD benefits in health insurance coverage.
3. Reduce discrimination towards people with HD.

Passage of the Huntington's Disease Parity Act in Congress is a primary objective of this Goal, but additionally, HDSA will work tirelessly to build an active and knowledgeable army of advocates that is engaged in educating law enforcement personnel on HD, providing resources for those applying for disability, and training the HD community about the Genetic Information Non-Discrimination Act (GINA).

### **Goal IV: Communicate comprehensive and credible HD information.**

As the largest non-profit organization dedicated to serving the Huntington's disease community, it is imperative that HDSA maximize its position as the primary source for all news, information, resources and education (HDSA and non-HDSA) related to Huntington's disease.

Our excellence is directly tied to our ability to be up-to-date and relevant, so that all those who come to us find the resources they seek and need. Importantly, the Society must be a comprehensive hub for the entire community, with links to resources outside the Society to underscore a "one-stop-shopping" experience.

To do this we will:

1. Enhance knowledge of HD and HD science.
2. Expand awareness of HDSA.
3. Increase awareness of HD among the general population.

In addition to our ongoing efforts and annual focus related to HD Awareness Month each May, the 50<sup>th</sup> Anniversary of HDSA's founding is a unique opportunity for HDSA to tell its story and engage new audiences. A comprehensive public relations effort and marketing campaign will bring visibility to our brand and story and therefore engage new audiences in our efforts.

### **Goal V: Increase volunteer engagement.**

People are our most important resource. Our volunteers represent the spirit and purpose of our Society, deliver important services and support, and ensure our growth. We recognize that it is imperative that we invest in strengthening and diversifying our volunteer base. Doing so will bolster our Chapters and Affiliates, enhance our programs and events, and expand our ability to impact more families.

We are committed to providing the appropriate training to our volunteers, supporting them with resources, and consistently showing appreciation for their good work. The fundamental strategies that will be implemented to increase our volunteer base are:

1. Strengthen the organizational dialog and operations.
2. Develop and retain knowledgeable HDSA leaders and volunteers.
3. Expand HDSA's organizational reach.
4. Identify and cultivate new volunteers.

The National Field Committee will continue to play an important role in the accomplishment of this Goal by developing personal one-on-one relationships with Chapter and Affiliate leadership. As a Committee of the National Board of Trustees, the NFC is instrumental in cultivating the community presence of HDSA and supporting its development through attentive development of volunteers.

From expanded resources on HDSA Connect to increased trainings online and at the Annual Convention, the organization will invest in the volunteers who bring the Society to life. Furthermore, in support of our mission to be accessible to all families, HDSA plans to have at least one Chapter or Affiliate in every state in the country.

### **Goal VI: Manage growth in a fiscally responsible manner.**

In order to provide for today and allow us to plan for tomorrow, the Society must operate in a manner that ensures its long-term health. We know that fiscal responsibility breeds trust that motivates our donors and allows us to achieve our mission. To accomplish this, we remain committed to timely payment of our financial obligations and to building the organization's operational reserves, so that we are a more stable, autonomous organization.

To do this we will:

1. Ensure funding of all financial obligations.
2. Grow the Board Operating Reserve to six months National operating expenses (according to non-profit best practices).
3. Increase unrestricted net assets.
4. Increase mission/administrative funding ratio to meet or exceed 80/20 percent.

Managing our cash flow and ensuring timely financial management in the Field will be vital to achieving this Goal. Additionally, funds will be regularly banked to establish financial reserves that protect the Society against risk and enable new program development.

**Goal VII: Increase revenue by at least 5% annually to grow organizational capacity.**

HDSA's programs are made possible by the financial support of our community, individuals, foundation and corporate supporters. In order for the Society to provide more advocacy, care, education and research, we must grow our fundraising.

From national campaigns to local special events, the Society is committed to increasing donations annually while keeping fundraising costs (aka costs to raise a dollar [CTRAD]) low. To achieve this success we will:

1. Expand our signature events, individual, corporate, and foundation giving programs throughout the organization.
2. Embrace technology to increase the opportunities for people to give to and engage with the Society.
3. Invest in a Planned Giving Program to establish long-term stability.

We will continue to broaden our donor base from inside and outside the Huntington's disease community, and redouble our commitment to our values of stewardship and accountability so that we continue to communicate clearly how our resources are changing lives.

**###**

**GOAL #1: ENHANCE AND DELIVER BEST PRACTICES IN HD FAMILY CARE**

**Strategy #1:** *Expand access to HD-experienced clinical care.*

**Objectives/Tactics:**

- 1.** Increase the number of HD SA Centers of Excellence (COE) across the United States.
- 2.** Increase the percentage of HD patients and families that receive their care at a COE.
- 3.** Identify the best clinical practices for management of HD symptoms.
- 4.** Increase access to psychiatric expert care for HD.
- 5.** Launch an HD SA-sponsored telemedicine program to ensure those unable to travel can still receive expert HD care.
- 6.** Better incorporate local physicians into HD SA Educational Days to improve their knowledge and awareness of HD SA resources, such as the Physician's Guide.

2017	2018	2019	2020	2021
Provide all HD SA COEs with "Info kits" to support HD families.	Award a total of 45 HD SA Centers of Excellence.	Double ancillary services, psychiatry and neurology online resource lists.	Award a total of 50 HD SA Centers of Excellence.	Provide care for at least 7,500 HD patients at COEs.
Ensure every HD SA Education Day includes a local HD clinician.	Develop clinical fellowship program to support young psychiatrists in COEs.	Award 1 <sup>st</sup> HD SA Psychiatric Fellowship.	Continue Psychiatric fellowship program, telemedicine, Clinical Practice TF, and resource development initiatives.	Support best care model established for management of HD symptoms.
Initiate pilot study to evaluate use of telemedicine to expand COE reach.	Evaluate telemedicine program and refine delivery.	Launch Clinical Practices Task Force to identify best practices in HD care.		

## Huntington's Disease Society of America Strategic Plan 2017-2021

### Strategy #2: Enhance social services and support resources.

#### Objectives/Tactics:

1. Identify gaps in essential HD services across the country and create new HD resources for caregivers and care providers.
2. Enhance delivery of HD services by educating and training both HDSA and non-HDSA social workers (SW).
3. Expand youth-specific support for HD community through growth of the National Youth Alliance (NYA) and by developing a nationwide network of youth-trained HD social workers.
4. Enhance programming at field-based educational events.
5. Host and broaden the impact and reach of the national community-wide, family-focused HD educational Convention.
6. Provide ongoing training to professional and lay Support Group Leaders.

2017	2018	2019	2020	2021
Increase access to professionally trained support groups in 5 underserved areas.	Develop HDSA moderated online support group for families without local access.	Develop and pilot regional SW Model to coordinate HD services in underserved areas.	Implement Regional SW Model to coordinate HD services in underserved areas.	Host an HD educational day in all HDSA Chapters and Affiliates.
Provide HD youth specific training to subset of HDSA Social Workers.	Incorporate NYA into all HDSA Education Days.	Evaluate and refine online support group program.	Utilization of HDSA Convention content (in person and online) increases by 20% from 2015 figures.	All support group leaders complete annual training.
Continue to host NYA Retreats in at least 3 locations nationwide.	Increase access to youth-trained HDSA Social Workers; monitor utilization.	Continue all NYA resources, including retreats and support groups.		Evaluate and continue regional social workers program. Ongoing delivery of youth services, professional development and Convention.
Maintain professional development activities at HDSA Convention.	Continue NYA Retreats and support group development.	Assure that 75 percent of support group leaders complete annual training.		



**Strategy #3:** *Improve access to long-term care facilities skilled in HD.*

**Objectives/Tactics:**

- 1.** Develop training programs to improve expertise of care provided to and quality of life (QoL) for persons with advanced HD, whether at home or in long-term care (LTC) facility.
- 2.** Advocate to improve QoL for persons with advanced HD.
- 3.** Increase outreach and educational efforts to LTC facilities about HD.
- 4.** Expand the number of LTC facilities and units specializing in HD across the country.

2017	2018	2019	2020	2021
<p>Increase Social Worker in-service trainings at LTC facilities by 10% over previous year.</p> <p>Survey HD families as to where loved ones currently reside and perform outreach to those LTC facilities.</p>	<p>Create advocacy strategy to work with Centers for Medicare &amp; Medicaid Services (CMS) to increase reimbursement rates.</p> <p>Increase Social Worker in-service trainings at LTC facilities by 10% over previous year.</p>	<p>Develop COE Program for LTC facilities.</p> <p>Increase Social Worker in-service trainings at LTC facilities by 10% over previous year.</p>	<p>Designate first HD/SA LTC COEs.</p> <p>Explore group home model of HD, including funding streams.</p> <p>Increase Social Worker in-service trainings at LTC facilities by 10% over previous year.</p> <p>Develop caregiver resources for advanced HD.</p>	<p>Continue LTC COE program and monitor impact on family access and QoL.</p> <p>Triple the number of LTC facilities in US specializing in HD care from end of 2016.</p> <p>Increase Social Worker in-service trainings at LTC facilities by 10% over previous year.</p>

## Huntington's Disease Society of America Strategic Plan 2017-2021

**Strategy #4:** *Increase access to counseling on key HD-related decisions, including genetic counseling and PGD-IVF.*

### Objectives/Tactics:

1. Ensure utilization of HD Genetic Testing Protocol that is current and reflective of care trends and family needs.
2. Educate community about preimplantation genetic diagnosis with *In-vitro* fertilization (PGD-IVF) as a family planning option.
3. Persuade insurance companies to provide coverage to HD families that desire to have children via PGD-IVF.

2017	2018	2019	2020	2021
Disseminate HDSA Genetic Testing Protocol to general practitioners and medical associations.	Organize 1 <sup>st</sup> annual professional training workshop for Genetic Counselors at Convention.	Organize committee to develop PGD-IVF program, including advocacy initiatives.	Launch PGD-IVF education program.	Publish update to HDSA Genetic Testing Protocol.
Identify all laboratories in US performing genetic testing for HD.	Educate genetic testing laboratories on genetic testing protocol for HD.	Continue genetic counselor and lab outreach and training.	Host meetings with key leaders/legislators regarding cost barriers to PGD-IVF.	Continue educational resources and programming regarding family planning and genetic testing.
Launch new content (online and in print) to assist HD families with family planning.			Survey changing trends in genetic testing.	

**Strategy #5:** *Grow network of and resources for HD specialized ancillary services, including occupational therapists, physical therapists, speech language pathologists and nutritionists.*

### Objectives/Tactics:

1. Develop Continuing Education Unit (CEU) Courses for ancillary service healthcare professionals.
2. Involve newly-trained ancillary service professionals in HD community.
3. Advertise HD educational opportunities with professional organizations/societies.

2017	2018	2019	2020	2021
Update and re-accredit HD101 course for healthcare professionals.	Create multi-part CEU course for speech language pathologists (SLP).	Double ancillary services, psychiatry and neurology online resource lists	Develop new CEU course for Occupational Therapists (OT) in conjunction with AOTA.	Develop quality of life research grant for ancillary services inside COE program.

## GOAL #2: ADVANCE HD RESEARCH

**Strategy #1:** *Ensure a pipeline of new HD researchers.*

### **Objectives/Tactics:**

1. Expand support for existing research programs targeting young investigators (basic or clinical) to build a pipeline of new researchers.
2. Foster collaboration between basic and clinical scientists by involving the HD SA Centers of Excellence in research programs.
3. Work with Scientific Advisory Board to identify critical voids in global HD research pipeline that could be positively impacted by new HD SA research investments.
4. Provide unique opportunities for HD SA-supported scientists to get out of laboratory and interact with HD patients and families.
5. Maintain our organizational research focus on understanding HD biology as it occurs in humans.

2017	2018	2019	2020	2021
Continue Human Biology Project and Don King Fellows.	Identify a new HD SA research grant opportunity and craft program description.	Launch/fund a new HD SA research grant opportunity.	Expand Donald King Summer Research Fellowship program to at least 5 awards.	Award minimum of \$1 million/year in grants to support the HD Human Biology Project.
Award HD Career Development Fellowship.	Expand Donald King Summer Research Fellowship program to at least 4 awards.		Award 2 HD Career Development Fellowships.	
Bring all HD SA supported researchers to Annual Convention to meet with HD families.				

**Strategy #2:** *Strengthen and build relationships with research collaborators.*

### **Objectives/Tactics:**

1. Educate the HD community on the latest HD research breakthroughs.
2. Position HD SA as the central source for nationwide HD community engagement in clinical research with pharmaceutical and biotechnology partners.
3. Identify new ways to work together with other HD or neuroscience organizations to accelerate drug development.
4. Establish more regular communications with all research organizations focused on HD.

## Huntington's Disease Society of America Strategic Plan 2017-2021

2017	2018	2019	2020	2021
<p>Continue to host annual HD Research Year in Review Webinar.</p> <p>Continue to host Research Forum at Annual Convention.</p> <p>Partner with rare disease and health advocacy organizations to communicate the importance of Patient Provided Information (PPIN) into clinical trial development.</p> <p>Partner with Think Genetic to expand online HD educational materials.</p>	<p>Expand partnership with CHDI Foundation to assist with clinical study awareness and recruitment.</p> <p>Leverage HDTrialFinder and PPIN to influence patient focused drug development.</p>	<p>Launch patient engagement project to survey patient attitudes, experience, impact and trends in HD family clinical research.</p>	<p>Host North American HD Patient Research Summit.</p>	<p>Continue to evaluate and utilize webinars, partnership and meetings to educate, engage and accelerate HD drug development.</p>

**Strategy #3:** *Fuel clinical research by ensuring active management in clinical studies.*

### Objectives/Tactics:

1. Increase US family participation rates in interventional and observational trials.
2. Build community understanding of HD research to motivate clinical research participation.
3. Develop patient-friendly resources about HD research and clinical trials.
4. Increase US awareness and participation in the global HD Clinical Trial Research platform, Enroll-HD.
5. Grow utilization of HDTrialFinder and associated Clinical Trial Navigator Call Center.

## Huntington's Disease Society of America Strategic Plan 2017-2021

2017	2018	2019	2020	2021
Build HDTrialfinder to 3000 users.  Increase HDTrialFinder call center usage by 20%.	Create patient-friendly materials for all recruiting HD clinical trials.	See US participation in Enroll-HD surpass Europe.	Expand HDTrialfinder to become a global resource for HD trial information	Build HDTrialfinder to 5000 users. Call Center volume to exceed 2016 rates by 20%.  Increase US clinical trial recruitment rates by 50% over 2016 levels.

**Strategy #4:** *Educate the community about the importance and impact of HD research.*

### Objectives/Tactics:

1. Promote clinical and observational research opportunities.
2. Develop patient friendly educational materials/resources on HD research.
3. Increase community involvement and perspectives in HD clinical trial protocol development.
4. Continue to host regular Research Webinars and other HD research symposia for community.
5. Continue organizational support for HD Buzz to bring research information to the community.

2017	2018	2019	2020	2021
Create an experimental medicine workshop for HDSA Convention.  Partner with HSC, HDA and EHA to create a Global HD Clinical Trial Advisory Council (CTAC).  Provide annual Research Champions Training.	Develop patient-friendly materials for all recruiting HD clinical trials listed in HDTrialfinder.  Partner with HDBuzz to provide regular clinical trial training/education to CTAC members and Research Champions Training.	Craft educational videos about importance of non-interventional research.  Maintain CTAC and Research Champion knowledge base and engagement.	Average 100 people in attendance of each HDSA Research Webinar.  Maintain CTAC and Research Champion knowledge base and engagement.	Double Research Champions roster over course of 5 years.

**GOAL #3: REMOVE BARRIERS TO QUALITY CARE**

**Strategy #1:** *Pass legislation that directly improves the quality of life for HD families.*

**Objectives/Tactics:**

1. Secure the passage and implementation of the HD Parity Act.
2. Advocate for health insurance companies to cover costs of PGD-IVF for HD gene positive individuals.
3. Make advocacy efforts an essential component of all HDSA Chapter/Affiliate activities.
4. Create ethically and legally sound standards for patients with HD to access Death with Dignity measures.

2017	2018	2019	2020	2021
Pass the HD Parity Act.  Develop a Death with Dignity workshop for National Convention.	Develop pilot project to advocate insurance companies to cover costs associated with PGD—IVF for HD families.	Identify an Advocacy Chairperson in each of HDSAs Chapters and Affiliates.  Develop a program to impact death with dignity legislation and educate community on Death with Dignity options.	Secure commitment from at least one national insurance company to cover costs associated with PGD-IVF.	Host HDSA Chapter /Affiliate Advocacy Chair training at Convention.

**Strategy #2:** *Expand HD benefits in health insurance coverage.*

**Objectives/Tactics:**

1. Collaborate with other organizations representing health conditions with similar symptoms (e.g., depression).
2. Educate HD community regarding changes in Social Security program that directly affect them.
3. Expand GINA to cover LTC and Life insurance protections.

## Huntington's Disease Society of America Strategic Plan 2017-2021

2017	2018	2019	2020	2021
Partner with SSA to educate disability examiners on new HD diagnostic criteria.	Create coalition to expand GINA protections.	Craft and introduce legislation with coalition to expand GINA.	Partner with organizations tackling cognitive, psychiatric and movement disorders to share educational resources.	Secure amendment to GINA to expand protections to HD patients.
Update website with FAQ regarding new SSA guidelines and changes to Medicare.				

### Strategy #3: Reduce discrimination towards people with HD.

#### Objectives/Tactics:

1. Update and implement Law Enforcement Educational and Awareness program.
2. Educate first responders (i.e. EMTs, emergency room professionals) about HD.
3. Educate correctional facilities about HD.
4. Improve HD care at acute psychiatric facilities through increased education.

2017	2018	2019	2020	2021
Evaluate impact and utilization of current Law Enforcement program.  Begin development of new Law Enforcement Education program and associated resources.	Launch new Law Enforcement Education program and related awareness campaign.  Develop resources specific for First Responders.	Develop new HD Family Navigator program to train community volunteers to interact/educate/train Law Enforcement and First Responders.	Create program for HD Psychiatry Fellows to conduct in-services at local psychiatric and correctional facilities.	Secure corporate funding to provide free HD ID bands to each and every HD patient that wants one.

**GOAL #4: COMMUNICATE COMPREHENSIVE AND CREDIBLE HD INFORMATION.**

**Strategy #1:** *Enhance knowledge of HD and HD science.*

**Objectives/Tactics:**

1. Communicate HD and HD science news in a timely manner utilizing all internal and external media relations tools including traditional print, TV and radio outreach as well as HDSA online and social media platforms.
2. Educate stakeholders on HD and relevant issues through promotion of HDSA's programs and campaigns.
3. Utilize visual tools (infographics, videos) to communicate HD impact.

2017	2018	2019	2020	2021
Continue to communicate all HDSA news at local HDSA events, on social media, on HDSA websites and with national and regional e-blasts.  Introduce new "meet the scientist" features.  Establish baseline of annual HD and HDSA media impressions and public awareness.	Roll out new HD multi-media library in conjunction with HDSA 50 <sup>th</sup> Anniversary campaign.	Increase media awareness by 10 percent as compared to 2016.  Increase use of video in news delivery.	Ongoing media outreach and promotional activities utilizing the newest, most relevant communications methods.	Increase media awareness by 10 percent as compared to 2019.

**Strategy #2:** *Expand awareness of HDSA.*

**Objectives/Tactics:**

1. Promote HDSA fundraising and educational events using all forms of local and national media (traditional and social).
2. Cultivate relationships with celebrities and other public figures to generate awareness.
3. Instill action through motivational messaging "Volunteer. Educate. Advocate. Donate."
4. Launch 50<sup>th</sup> Anniversary Campaign to tell organization's history and impact.



## Huntington's Disease Society of America Strategic Plan 2017-2021

2017	2018	2019	2020	2021
Expand HDSA Connect media resources, including new systems for media list requests.  Prep 50 <sup>th</sup> Anniversary campaign, including volunteer training.  Promote HDSA Fundraising and Educational Events through social media (National and Local - Twitter, Facebook, Instagram, Snapchat), through National and Local Websites.	Launch 50 <sup>th</sup> Anniversary Campaign to increase visibility of HDSA and all of its events, programs and resources.	Assess impact of 50 <sup>th</sup> Anniversary messaging.  Ongoing promotion of HDSA events and programs.	Ongoing media outreach and promotional activities utilizing the newest, most relevant communications methods.	Increase media awareness by 10 percent as compared to 2019.

**Strategy #3:** *Increase awareness of HD among the general population.*

### Objectives/Tactics:

1. Build on the *Family is Everything* theme to personalize HD to people who are not familiar with it.
2. Utilize HDSA's musical heritage to introduce new audiences to HD.
3. Promote relationship between HD and other neurodegenerative diseases.

2017	2018	2019	2020	2021
Expand <i>Guthrie Sessions</i> and musical-heritage related outreach.	Feature Guthrie history in HDSA at 50 campaign.  Launch online digital archives.	Launch "why HD" campaign with notable scientists to raise awareness of HD's relationship with other ND diseases.	Build on ongoing musical and scientific storytelling initiatives.	Measure public awareness of HD as compared to 2017 figures.

**GOAL #5: INCREASE VOLUNTEER ENGAGEMENT**

**Strategy #1:** *Strengthen the organizational dialog and operations.*

**Objectives/Tactics:**

1. Build relationship between NFC and Chapter & Affiliate leaders.
2. Support Chapter & Affiliate Agreement implementation.
3. Invest in and increase use of HDSA Connect, webinars and other internal community content resources.

2017	2018	2019	2020	2021
<p>Host annual Leadership Day at Convention (ongoing)</p> <p>Host NFC Retreat and refine role of NFC.</p> <p>Achieve 100% submission of Chapter &amp; Affiliates Agreements.</p> <p>Update and maintain valuable HDSA resources found on HDSA Connect (Agreements, Volunteer Welcome Kit, Memo's, How To's, Manuals, and other materials to support their great work locally).</p>	<p>Launch new NFC partner program to encourage communication between Chapter/Affiliate leaders and their NFC reps.</p> <p>Develop new online volunteer resources using multi-media (i.e. podcasts) to support the volunteer leader relationship between NFC members and field-based volunteer leaders.</p> <p>Maintain HDSA Connect library with most current information.</p>	<p>Conduct regional leadership meetings (like 2015-2016).</p> <p>Continue to invest in volunteer leadership program development with educational content and NFC outreach.</p>	<p>Evaluate implementation of agreements.</p> <p>Increase NFC Roster to 12 volunteer leaders.</p>	<p>Host NFC Retreat and continue to assess volunteer development needs.</p>

## Huntington's Disease Society of America Strategic Plan 2017-2021

**Strategy #2:** *Develop and retain knowledgeable HD SA leaders and volunteers.*

### Objectives/Tactics:

1. Build and implement volunteer training curriculum for new Chapter & Affiliate leaders and volunteers.
2. Utilize technology to provide ongoing communication and engagement tools.
3. Develop regular leadership forums (CEO webinars, regional teleconferences) to provide direct communication between volunteer and staff leadership.
4. Define and promote pathway of growth for volunteers that reaches from local event involvement to National Board membership.

2017	2018	2019	2020	2021
Update Volunteer Leadership Kit.	Launch Volunteer of the Year award.	Implement new National Board nominations process to highlight field volunteer opportunities at national level.	Host Volunteer Engagement Webinars- featuring hot topics relating to events, board development, grants, volunteer engagement, etc.	Update volunteer development program and showcase leaders who graduated from within the organization to national leadership.
Host monthly calls with Chapter or Affiliate leaders to open lines of communications and share ideas for growth.	Launch new volunteer development program with emphasis on intra-organizational growth and highlighting NYA.	Maintain volunteer development program and Volunteer of the Year Award.		
Continue to host Bi-Annual CEO Webinars.	Revamp CEO webinars with more interactive "ask" features including live video options.			

**Strategy #3:** *Expand HD SA's Organizational Reach.*

### Objectives/Tactics:

1. Establish at least one Chapter or Affiliate in each state.
2. Ensure Affiliates grow to Chapter status consistent with the Agreements.
3. Cultivate and spur relationships between Chapters, Affiliates, their local Centers of Excellence and support groups to strengthen community-based organizing.

## Huntington's Disease Society of America Strategic Plan 2017-2021

2017	2018	2019	2020	2021
Add at least 2 new Chapters and 1 new Affiliate.	Add at least 2 new Chapters and 1 new Affiliate.	Add at least 2 new Chapters and 1 new Affiliate.	Add at least 2 new Chapters and 1 new Affiliate.	Achieve establishment of at least one HDSA Chapter or Affiliate in all 50 States.
At least 50 percent of Chapters/Affiliates have a direct relationship with a local COE.		At least 75 percent of Chapters/Affiliates have a direct relationship with a local COE.		100 percent of Chapters/Affiliates have a direct relationship with a local COE.

**Strategy #4:** *Identify and cultivate new volunteers.*

### Objectives/Tactics:

1. Celebrate and communicate appreciation for HDSA volunteers.
2. Train event organizers on volunteer recruitment strategies with an emphasis on corporate team cultivation.
3. Break down silos between inter-organizational volunteer groups (advocacy, NYA, event donors) to increase engagement of existing volunteers and encourage cultivation of relationships.

2017	2018	2019	2020	2021
Promote and celebrate "Thank you Thursdays" and Chapter and Affiliate Leadership Awards at Convention (ongoing).  Implement regional volunteer recognition program.  Welcome 500 new volunteers annually.	Tie regional volunteer program into national Volunteer of the Year Award program.  Welcome 600 new volunteers.	Conduct a volunteer participation study to evaluate retention, frequency of involvement and unmet interest areas.  Welcome 700 new volunteers.	Use study results to launch new "I am HDSA" program to build volunteer identity and engagement.  Welcome 800 new volunteers.	Continue "I am HDSA" campaign.  Ongoing monitoring of volunteer retention.  Welcome 900 new volunteers.

**GOAL #6: MANAGE GROWTH IN A FISCALLY RESPONSIBLE MANNER**

**Strategy #1:** *Ensure funding of all financial obligations.*

**Objectives/Tactics:**

1. Budget grant awards based on planned activities.
2. Plan payment timeline with the cash flow schedule and grant milestones.
3. Maintain funds in operating account for ongoing financial obligations and money market account for larger payments.
4. Schedule consistent cash distributions from Chapters and Regions.

2017	2018	2019	2020	2021
Complete cash flow schedule for FY2017 with tracking of cash distributions from chapters/regions.	Complete cash flow schedule for FY2018 with tracking of cash distributions from chapters/regions.	Complete cash flow schedule for FY2019 with tracking of cash distributions from chapters/regions.	Complete cash flow schedule for FY2020 with tracking of cash distributions from chapters/regions.	Complete cash flow schedule for FY2021 with tracking of cash distributions from chapters/regions.
Schedule bi-weekly and quarterly payments for operating expenses and grants.	Schedule bi-weekly and quarterly payments for operating expenses and grants.	Schedule bi-weekly and quarterly payments for operating expenses and grants.	Schedule bi-weekly and quarterly payments for operating expenses and grants.	Schedule bi-weekly and quarterly payments for operating expenses and grants.
Track account balances in the operating and money market accounts to ensure cash availability for all payments.	Track account balances in the operating and money market accounts to ensure cash availability for all payments.	Track account balances in the operating and money market accounts to ensure cash availability for all payments.	Track account balances in the operating and money market accounts to ensure cash availability for all payments.	Track account balances in the operating and money market accounts to ensure cash availability for all payments.

## Huntington's Disease Society of America Strategic Plan 2017-2021

**Strategy #2:** *Grow Board Operating Reserve to six months of National operating expenses.*

### Objectives/Tactics:

1. Budget annually for a surplus for funding of the Board Operating Reserve Fund.
2. Increase investment income on the Board Operating Reserve Fund accounts.
3. Revise investment policy to govern the investment of funds in the Board Operating Fund.

2017	2018	2019	2020	2021
Assess the targeted investment needed for the six months of funding to the Board Operating Reserve Fund from the approved budget report.	Assess the targeted investment needed for the six months of funding to the Board Operating Reserve Fund from the approved budget report.	Assess the targeted investment needed for the six months of funding to the Board Operating Reserve Fund from the approved budget report.	Assess the targeted investment needed for the six months of funding to the Board Operating Reserve Fund from the approved budget report.	Assess the targeted investment needed for the six months of funding to the Board Operating Reserve Fund from the approved budget report.
Increase the Board Operating Reserve Fund with incremental deposits of at least \$100K - \$200K in an interest bearing account.	Increase the Board Operating Reserve Fund with incremental deposits of at least \$100K - \$200K in an interest bearing account.	Increase the Board Operating Reserve Fund with incremental deposits of at least \$100K - \$200K in an interest bearing account.	Increase the Board Operating Reserve Fund with incremental deposits of at least \$100K - \$200K in an interest bearing account.	Increase the Board Operating Reserve Fund with incremental deposits of at least \$100K - \$200K in an interest bearing account.
Review the HDSA Investment Policy and updated as needed.	Review the HDSA Investment Policy and updated as needed.	Review the HDSA Investment Policy and updated as needed.	Review the HDSA Investment Policy and updated as needed.	Review the HDSA Investment Policy and updated as needed.
Review market conditions and internal financial statements to determine changes to the investments.	Review market conditions and internal financial statements to determine changes to the investments.	Review market conditions and internal financial statements to determine changes to the investments.	Review market conditions and internal financial statements to determine changes to the investments.	Review market conditions and internal financial statements to determine changes to the investments.

## Huntington's Disease Society of America Strategic Plan 2017-2021

### Strategy #3: *Increase unrestricted net assets.*

#### Objectives/Tactics:

1. Revise fundraising communications strategies for increased unrestricted donations.
2. Monitor activities annually for maximum release of temporarily restricted revenue.
3. Match temporarily restricted donations with expenses.

2017	2018	2019	2020	2021
Review new fundraising strategies and track the increased unrestricted donations.	Review new fundraising strategies and track the increased unrestricted donations.	Review new fundraising strategies and track the increased unrestricted donations.	Review new fundraising strategies and track the increased unrestricted donations.	Review new fundraising strategies and track the increased unrestricted donations.
Monitor the revenue coding throughout the fiscal year to ensure accuracy of the increase and release of restricted assets.	Monitor the revenue coding throughout the fiscal year to ensure accuracy of the increase and release of restricted assets.	Monitor the revenue coding throughout the fiscal year to ensure accuracy of the increase and release of restricted assets.	Monitor the revenue coding throughout the fiscal year to ensure accuracy of the increase and release of restricted assets.	Monitor the revenue coding throughout the fiscal year to ensure accuracy of the increase and release of restricted assets.
Match all current restricted donations to the expenses annually for maximum release of restricted assets.	Match all current restricted donations to the expenses annually for maximum release of restricted assets.	Match all current restricted donations to the expenses annually for maximum release of restricted assets.	Match all current restricted donations to the expenses annually for maximum release of restricted assets.	Match all current restricted donations to the expenses annually for maximum release of restricted assets.
Update and distribute Fundraising Guidelines for the Society (detailing the How To's of hosting an event according to IRS guidelines as well as highlighting the importance of unrestricted donations).				



## Huntington's Disease Society of America Strategic Plan 2017-2021

Discuss Unrestricted Donations at Leadership Day, in budget documents, in annual Finance Webinar and on CEO Webinar.				
--	--	--	--	--

**Strategy #4:** *Increase mission/administrative funding ratio to meet or exceed 80/20 percent.*

### Objectives/Tactics:

1. Monitor results of all fundraising activities to maximize mission return.
2. Continue to educate staff and volunteers on the importance of cost to raise a dollar.
3. Review monthly financial reports with staff and volunteers to improve communications and budget management.

2017	2018	2019	2020	2021
Review and manage all budgeted results monthly to ensure all events were within the appropriate 80/20 fundraising ratio by providing volunteers and staff with the appropriate reporting results.	Review and manage all budgeted results monthly to ensure all events were within the appropriate 80/20 fundraising ratio by providing volunteers and staff with the appropriate reporting results.	Review and manage all budgeted results monthly to ensure all events were within the appropriate 80/20 fundraising ratio by providing volunteers and staff with the appropriate reporting results.	Review and manage all budgeted results monthly to ensure all events were within the appropriate 80/20 fundraising ratio by providing volunteers and staff with the appropriate reporting results.	Review and manage all budgeted results monthly to ensure all events were within the appropriate 80/20 fundraising ratio by providing volunteers and staff with the appropriate reporting results.
Present budget management information at Annual convention presentation on Leadership Day to highlight cost to raise a dollar topic.	Present budget management information at Annual convention presentation on Leadership Day to highlight cost to raise a dollar topic.	Present budget management information at Annual convention presentation on Leadership Day to highlight cost to raise a dollar topic.	Present budget management information at Annual convention presentation on Leadership Day to highlight cost to raise a dollar topic.	Present budget management information at Annual convention presentation on Leadership Day to highlight cost to raise a dollar topic.
Recognize volunteer leadership in expense management with new award at Convention.	Ensure the approved budget for 2019 listed all events within the appropriate ratio.	Ensure the approved budget for 2020 listed all events within the appropriate ratio.	Ensure the approved budget for 2021 listed all events within the appropriate ratio.	Ensure the approved budget for 2022 listed all events within the appropriate ratio.



Ensure the approved budget for 2018 listed all events within the appropriate ratio.				
---	--	--	--	--

**GOAL #7: INCREASE REVENUE BY AT LEAST 5% ANNUALLY TO GROW ORGANIZATIONAL CAPACITY**

**Strategy #1:** *Expand our signature events, individual, corporate, and foundation giving programs throughout the organization.*

**Objectives/Tactics:**

1. Explore new revenue streams for adding additional Signature Events to engage and increase community involvement with an eye on new audience development.
2. Increase the number of individual donors through all fundraising initiatives.
3. Develop a case statement and marketing campaign that encourages unrestricted giving.
4. Launch Major Giving initiative tied to 50<sup>th</sup> Anniversary of HDSEA.
5. Expand Corporate support base and increase Corporate support with new partnerships to support national and regional initiatives.
6. Collaborate with Mission team to identify programs and services attractive to Foundation support.
7. Regularly communicate the value in growing the organizational capacity.
8. Maintain and expand donor stewardship and cultivation programs.

2017	2018	2019	2020	2021
Develop new Signature Event concept with the community through brainstorming unique ideas with key leaders.	Pilot new Signature Event program in up to 5 key markets.	Based on year-one learnings, expand new Signature Event program by 10%.	Continue roll out of new event program.	Continue roll out of new event program with goal of 20 events in year three of roll out.
Develop 50 <sup>th</sup> Anniversary giving campaign with focus on unrestricted giving.	Launch 50 <sup>th</sup> Anniversary giving campaign.	Increase number of major donors by 20% over 2016.	Introduce major donor recognition society.	School program implemented in at least one community in every Chapter.
Research and pilot school-based giving program (3 schools).	Expand school-based giving program to 10 schools.	Expand school-based program to 25 schools.	School program implemented in at least one community in every region.	Ensure Team Hope net revenue has increased by 20% over 2016 figures.
Increase Team Hope net revenue by 5 percent annually.	Develop \$50K incentive program for Team Hope Walks in conjunction with the 50 <sup>th</sup> Anniversary.	Secure at least 3 national sponsors for Team Hope.	Host at least one Team Hope Walk in every state.	Secure at least 5 national Team Hope sponsors.
		Increase Celebration of Hope revenue by 5 percent over prior year.	Pilot mini-Celebration of Hope model for communities with Level 3	

## Huntington's Disease Society of America Strategic Plan 2017-2021

<p>Feature workplace giving campaigns to build awareness and increase participation.</p> <p>Diversify corporate support with relationships with 5 new companies.</p> <p>Increase corporate giving by 5% over 2016.</p> <p>Evaluate Foundation giving potential for Society.</p> <p>Maintain Individual giving appeals (direct mail and sweeps) with conservative growth forecasted at 3% annually.</p>	<p>Hold Celebrations of Hope in every area where there is a Level 1 or 2 HDSDA Center of Excellence.</p> <p>Feature in-kind giving opportunities; train volunteers on types of gifts and appropriate recognition.</p> <p>Increase corporate development (diversification of partners and funds) 10%.</p> <p>Allocate resources to increase Foundation giving by 20%.</p>	<p>Increase corporate development (diversification of partners and funds) 5%.</p> <p>Evaluate and adjust Foundation outreach approach. Achieve 10% increase over prior years Foundation revenue.</p>	<p>COEs.</p> <p>Increase corporate development (diversification of partners and funds) 5%.</p> <p>Achieve 5% increase over prior years Foundation revenue.</p>	<p>A third of communities with Level 3 COEs host mini-COH events.</p> <p>Increase corporate development (diversification of partners and funds) 5%.</p> <p>Achieve 5% increase over prior years Foundation revenue.</p>
--	--	--	--	---

**Strategy #2:** Embrace technology to increase the opportunities for people give to and engage with the Society.

### Objectives/Tactics:

1. Encourage more people to give regular gifts online.
2. Work collaboratively with Communications Department to integrate fundraising strategy into all web, app and social media based outreach.
3. Increase response to e-fundraising appeals.

## Huntington's Disease Society of America Strategic Plan 2017-2021

2017	2018	2019	2020	2021
<p>Build upon partnership with DonorDrive to enhance online giving for all HD SA events, accept international credit cards, promptly and accurately process thank you and tax receipts.</p> <p>Ensure we are maximizing all current community partner relationships (i.e. Facebook for Non-Profits, iGive, AmazonSmile)</p> <p>Launch affiliated online giving campaigns, like Coin Up, for complementary giving.</p> <p>Promote successful online donation campaigns through social media marketing tools such as blogging, podcasting, Facebook, YouTube, Twitter, message boards, and wikis.</p>	<p>Implement successful electronic giving component to all direct mail appeals.</p> <p>Increase traffic to HD SA marketplace and community partners by 10%.</p> <p>Monitor ongoing online giving relationships, vendors and affiliated giving programs.</p>	<p>Drive increase in all affiliated and online marketplace partnerships by at least 5% over previous year.</p> <p>Actively seek new fundraising resources for HD families.</p>	<p>Drive increase in all affiliated and online marketplace partnerships by at least 5% over previous year.</p> <p>Actively seek new fundraising resources for HD families.</p>	<p>Drive increase in all affiliated and online marketplace partnerships by at least 5% over previous year.</p> <p>Actively seek new fundraising resources for HD families.</p>

## Huntington's Disease Society of America Strategic Plan 2017-2021

**Strategy #3:** *Invest in a planned giving program to establish long-term stability.*

**Objectives/Tactics:**

1. Continue to conduct targeted appeals to individuals that are current donors who may be prospects for planned gifts.
2. Incorporate 50<sup>th</sup> Anniversary messages into planned giving campaigns to encourage planning for long-term stability of the Society.
3. Collaborate with Field Staff to raise awareness of Planned Giving impact and giving opportunities.

2017	2018	2019	2020	2021
<p>Train volunteer leaders on planned giving and provide field-based resources to encourage such gifts.</p> <p>Conduct annual outreach to prospects featuring recent bequests to highlight impact.</p>	<p>Feature planned giving in 50<sup>th</sup> Anniversary campaign.</p> <p>Conduct annual outreach to prospects featuring recent bequests to highlight impact.</p>	<p>Ensure regional leadership retreats includes development training and planned giving resources.</p> <p>Conduct annual outreach to prospects featuring recent bequests to highlight impact.</p>	<p>Highlight planned givers in "I am HD SA" Campaign.</p> <p>Conduct annual outreach to prospects featuring recent bequests to highlight impact.</p>	<p>Conduct annual outreach to prospects featuring recent bequests to highlight impact.</p>

###

### Strategic Plan 2017-2021: Glossary of Terms

The following Glossary of Terms has been compiled to accompany the HDSA Strategic Plan 2017-2021 and serves as a handy reference as you navigate abbreviations and acronyms throughout the Plan.

1. **Caregivers Corners** – An HDSA online webinar program for caregivers that covers topics specifically related to caring for an HD family.
2. **CHDI** – A private, not-for-profit research organization working with an international network of scientists to discover drugs that slow the progression of Huntington's disease. [www.chdifoundation.org](http://www.chdifoundation.org)
3. **CME** – *Continuing Medical Education*: A specific form of continuing education for medical practitioners maintain competence and learn new skills.
4. **COE** – HDSA *Centers of Excellence* program, also referred to as “the Centers.”
5. **COH** – *Celebrations of Hope*: HDSA fundraising events which showcase the HDSA Centers of Excellence program.
6. **CMS** – U.S. *Centers for Medicare & Medicaid Services*. The federal provider of health care benefits to more than 100 million Americans. [www.cms.gov](http://www.cms.gov)
7. **CTRAD** – *Cost to raise a dollar*: A business calculation used to assess the net impact of funds raised from an event in which the cost to run an event is divided by the gross revenue of that event. For example, if an event raised \$20,000 but cost \$5,000 to run, the cost to raise a dollar is 0.25 cents per dollar or an expense ratio of 25 percent.
8. **DKF** – *Donald A. King, Fellowship*: An HDSA research fellowship program for graduate students awarded annually each summer. The program was named for HDSA's past Chairman Don King.
9. **DonorDrive** – HDSA's online peer-to-peer fundraising software for events like Team Hope walks.
10. **E-advocacy** – A method of advocating for public policy that is done completely using online tools, such as online letter-writing or email campaigns.
11. **EHDN** – *European HD Network*: A platform for professionals and people affected by HD and their relatives to facilitate working together throughout Europe. [www.euro-hd.net](http://www.euro-hd.net)
12. **Enroll-HD** – A worldwide observational study for Huntington's disease families. It will monitor how the disease appears and changes over time in different people, and is open to people who either have HD or are at-risk. [www.enroll-hd.org](http://www.enroll-hd.org)
13. **FY** – Shorthand for “fiscal year.” HDSA's fiscal year runs from January 1<sup>st</sup> to December 31<sup>st</sup> each year.
14. **GINA** – *Genetic Information Non-discrimination Act*: A federal law passed in 2008 to protect Americans against discrimination based on their genetic information when it comes to health insurance and employment.
15. **GT** – Shorthand for *genetic testing*.
16. **HBP** – *HDSA Human Biology Project*. An HDSA research program aimed at supporting scientific study of HD biology as it occurs in humans.
17. **HD** – *Huntington's disease*.
18. **HDA** – *Huntington Disease Association*. HDSA's counterpart in England & Wales. [www.hda.org.uk](http://www.hda.org.uk)

19. **HDBuzz** – An HDSA-supported global internet portal for the rapid dissemination of high-quality Huntington's disease research news, written in plain language, by HD clinicians and scientists. [www.hdbuzz.net](http://www.hdbuzz.net)
20. **HDSA** – *Huntington's Disease Society of America*, Inc; also referred to as "the Society." [www.hdsa.org](http://www.hdsa.org)
21. **HDSA Connect**– A password-protected website for HDSA leadership, i.e. the Board of Trustees, National Field Committee and Chapter and Affiliate leadership, to share organizational resources.
22. **HDSA Research Champions**– HDSA program to develop community-based advocates who speak about their experiences participating in HD clinical research.
23. **HDTrialFinder.org** – A web-based clinical trial matching service for the HD community by the HD community. [www.hdtrialfinder.org](http://www.hdtrialfinder.org)
24. **HDYO** – *Huntington's Disease Youth Organization*. An HDSA-supported international non-profit organization set up to specifically provide support for young people around the world impacted by Huntington's disease. [www.hdyo.org](http://www.hdyo.org)
25. **HSC** – *Huntington Society of Canada*: HDSA's counterpart in Canada. [www.huntingtonsociety.ca](http://www.huntingtonsociety.ca)
26. **HSG** – *Huntington Study Group*: A non-profit group of physicians and other health care providers from medical centers in the United States, Canada, Europe, Australia, New Zealand and South America, experienced in the care of Huntington patients and dedicated to clinical research of Huntington disease. [www.huntingtonstudygroup.org](http://www.huntingtonstudygroup.org)
27. **IHA** – *International Huntington Association*: A federation of national voluntary health agencies that share common concern for individuals with Huntington's disease (HD) and their families. [www.huntington-disease.org](http://www.huntington-disease.org)
28. **JHD** – *Juvenile Huntington's disease*. Also known as juvenile-onset HD.
29. **LTC** – *Long-Term Care*, as in "LTC facilities."
30. **NFC** – *National Field Committee*: A volunteer committee of HDSA focused on supporting the Chapters and Affiliates of the Society.
31. **NHC** – *National Health Council*: A Coalition of more than 100 disease-specific health non-profits providing a unified voice for Americans living with chronic disease and their caregivers. HDSA is a member of the NHC. [www.nationalhealthcouncil.org](http://www.nationalhealthcouncil.org)
32. **NIH** – *National Institutes of Health*: A part of the U.S. Department of Health and Human Services, it is the nation's medical research agency. [www.nih.gov](http://www.nih.gov)
33. **NINDS** – *National Institute of Neurological Disorders and Stroke*: A division of the National Institutes of Health focused on research into neurological disorders including Huntington's disease. [www.ninds.nih.gov](http://www.ninds.nih.gov)
34. **NORD** – *National Organization of Rare Diseases*: A federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. [www.rarediseases.org](http://www.rarediseases.org)
35. **NYA** – *HDSA National Youth Alliance*: HDSA's youth education and support program for all youth up to age 29 who are in HD families. [www.nya.hdsa.org](http://www.nya.hdsa.org)
36. **PCP** – *Primary care physician*. Also known as a GP or general practitioner.
37. **PGD** – *Preimplantation Genetic Diagnosis*. Often referenced as PGD-IVF (in vitro fertilization) to describe a family planning technique for HD families.
38. **PPIN** – Acronym for *Patient Provided Information*, a formal term often used by the FDA to describe the process of incorporating patient experience into the drug development process.

- 39. **QoL** – An abbreviation for “*Quality of Life*.”
- 40. **RFP** – *Request for proposal*: Primarily used by the Society to solicit applications for research funding.
- 41. **SAB** – *Scientific Advisory Board*. An HDSA volunteer committee comprised of physicians and scientists who advise the Society on issues related to HD medicine and research.
- 42. **SG** – Organizational shorthand for “*Support Group*.”
- 43. **SSA** – *Social Security Administration*: A division of the U.S. government dedicated to delivering social services, including disability, to the American public. [www.ssa.gov](http://www.ssa.gov)
- 44. **SW** – Organizational shorthand for “*Social Worker*.”
- 45. **TBA** – An abbreviation of the phrase “*to be announced*.”
- 46. **Team Hope** – HDSA’s signature event Walk program to raise funds for the HDSA mission. [www.hdsa.org/teamhope](http://www.hdsa.org/teamhope)
- 47. **TF** – Organizational shorthand for “*Task Force*.”
- 48. **Thank you Thursdays** – Volunteer appreciation events to recognize supporters of HDSA.



## HDSA Strategic Plan 2012-17: Outcomes Report

Goal	Strategy	Outcomes
I. Build HD <i>Community-Service Organization</i>	Expand access to top clinical care.	<ul style="list-style-type: none"> <li>Grew HDSA Center of Excellence from 21 in 2012 to 39 grantees in 2016.</li> <li>Relaunched HDSA Center of Excellence program to include more consistent reporting from each Center to inform best practice development.</li> <li>Developed and maintained robust referral list available through the HDSA Helpline and online at HDSA.org.</li> </ul>
	Enhance social services and support resources.	<ul style="list-style-type: none"> <li>Restructured HDSA Social Worker team to facilitate greater sharing and complement to regional services.</li> <li>Conducted education and outreach to non-HDSA funded Social Workers and ancillary service providers, including development of continuing education programs for physical and occupational therapists.</li> <li>Devoted more resources to the HDSA National Youth Alliance (NYA) and hosted regional retreats to broaden support for HD youth community.</li> <li>Launched HDSA Educational Event curriculum and consistent resources for more than 30 local annual events.</li> </ul>
	Improve access to long-term care facilities skilled in HD.	<ul style="list-style-type: none"> <li>Convened Workgroup on long-term care needs and issues report on key learnings and focused needs for families and care providers.</li> <li>Published <i>Professional Guide for Long-Term Care Facilities</i>.</li> </ul>
	Increase access to counseling on key HD-related decisions (clinical and logistical).	<ul style="list-style-type: none"> <li>Published new updated <i>Genetic Testing Protocol for Huntington's Disease</i> in 2016.</li> <li>Established ongoing partnership with the U.S. Social Security Administration to support disability needs of HD families.</li> <li>Educated families on health care access changes and insurance choices resulting from the Affordable Care Act.</li> <li>Provided ongoing support to families regarding financial planning and discrimination concerns (i.e. GINA).</li> </ul>

<b>II. Support HD Research &amp; Communicate its Impact</b>	Ensure pipeline of new HD researchers.	<ul style="list-style-type: none"> <li>• Launched HDSA HD Human Biology Project to fund innovative, clinically-collaborative and human-based study of HD.</li> <li>• Annually awarded <i>Donald A. King, Fellowships</i> to young scientists to cultivate interest in the field of HD study.</li> </ul>
	Strengthen and build partnerships with research partners.	<ul style="list-style-type: none"> <li>• Launched HDSA Research Webinar series to educate families about HD science and the impact of HDSA collaborators.</li> <li>• Increased research-specific content at the Annual HDSA Convention.</li> <li>• Continued to cultivate strong partnerships with key HD research organizations including the CHDI Foundation and the Huntington Study Group.</li> </ul>
	Establish a dynamic and reputable set of advisors to proactively position Society's lead role in discovery.	<ul style="list-style-type: none"> <li>• Established and maintained HDSA Scientific Advisory Board of diverse and world-renowned scientists to guide HDSA's research portfolio.</li> </ul>
	Fuel clinical research by ensuring active enrollment in clinical studies.	<ul style="list-style-type: none"> <li>• Launched HD TrialFinder, a clinical trial matching service for HD-specific clinical science, in partnership with other HD organizations.</li> <li>• Hosted Clinical Trial Showcase at the Annual HDSA Convention to discuss clinical research opportunities.</li> <li>• Developed clinical research resources for use at HDSA community-based educational events.</li> <li>• Launched HDSA Research Champions, a network of HD family volunteers who advocate for clinical trial participation among their peers.</li> </ul>

<b>III. Remove Barriers to Quality Care</b>	<p>Pass legislation that directly improves the quality of life of HD families.</p>	<ul style="list-style-type: none"> <li>Secured Compassionate Allowance designation of both Adult and Juvenile Onset Huntington's disease by the U.S. Social Security Administration.</li> <li>Continued to advocate for passage of the HD Parity Act, which is reintroduced each Congressional session with robust bipartisan support.</li> <li>Grew HDSA Advocacy network to more than 13,000 active individuals.</li> </ul>
	<p>Expand HD benefits in health insurance coverage.</p>	<ul style="list-style-type: none"> <li>Supported roll-out of Health Insurance Exchange, a component of the Affordable Care Act.</li> <li>Continued to monitor for preservation of essential health benefits, no-lifetime caps for coverage, and coverage of pre-existing conditions.</li> </ul>
	<p>Reduce discrimination towards people with HD.</p>	<ul style="list-style-type: none"> <li>Launched Law Enforcement Toolkit to facilitate communication and education between HD families and their local law enforcement professionals.</li> <li>Hosted webinars and educational sessions on legal matters, GINA and navigating disability. All resources are archived on HDSA.org as part of an enduring library.</li> <li>Introduced Professional Resources section of the HDSA.org website for clinicians and professional care providers.</li> </ul>
	<p>Increase the number of HD specialized physicians and related care providers.</p>	<ul style="list-style-type: none"> <li>Launched online HD101 Continuing Medical Education program for primary care providers and community-based neurologists.</li> </ul>

<b>IV. Become Premier Communicator of HD Information</b>	<p>Enhance knowledge of HD and HD science.</p>	<ul style="list-style-type: none"> <li>• Launched HD News app for mobile devices to aggregate HD related information for consumers.</li> <li>• Continued to provide grant support to HDBuzz to facilitate community understanding of HD news.</li> <li>• Featured HDSA-funded scientists at Annual HDSA Convention.</li> <li>• Annually published HDSA Research Report and ensured HD science information was consistently communicated in all HDSA publications.</li> </ul>
	<p>Increase awareness of HD among the general population.</p>	<ul style="list-style-type: none"> <li>• Used “Faces of HD” and #LetsTalkAboutHD campaigns to build personal story telling about HD and increase community-based awareness.</li> <li>• Engaged national spokespeople to create library of HD public service announcements.</li> <li>• Launched <i>HDSA Guthrie Sessions</i> program, a social media performance outlet for rising musicians to leverage the Guthrie legacy to raise awareness of HD.</li> </ul>
	<p>Expand awareness of HDSA.</p>	<ul style="list-style-type: none"> <li>• Relaunched HDSA.org as a family-focused resource hub.</li> <li>• Built largest HD social media community on Facebook with complementary engagement on Twitter, YouTube and evolving social media platforms.</li> <li>• Introduced “Family is Everything” slogan to re-center all HDSA communications around the family-centered mission of the Society.</li> <li>• Managed HDSA brand effectively with new suite of HDSA publications, promotional templates and brand management tools.</li> </ul>

V. Grow Volunteer Involvement	Strengthen relationships between National and Chapters & Affiliates.	<ul style="list-style-type: none"> <li>Developed HDSA Agreements for all Chapters and Affiliates which clearly explain the relationships and expectations between the National and Field-based HDSA teams.</li> <li>Increased the role of the HDSA National Field Committee to build strong ongoing dialogue with Chapter and Affiliate leaders.</li> <li>Hosted collaborative and educational Leadership Days at Annual HDSA Convention.</li> <li>Introduced HDSA CEO Webinar series to increase direct communication between field volunteers and staff leadership.</li> </ul>
	Establish comprehensive local network of knowledgeable HDSA volunteers.	<ul style="list-style-type: none"> <li>Hosted regional meetings for all local leadership to meet with National Trustees and staff.</li> <li>As part of the HDSA Agreements, established clear expectations for Affiliates to grow to become Chapters.</li> <li>Continued to add new HDSA Chapters and Affiliates annually.</li> </ul>
	Deploy "HD Army" to give voice and action to HD causes and needs.	<ul style="list-style-type: none"> <li>Utilized HDSA Connect, Regional teleconferences and topical webinars to increase engagement and knowledge on HDSA and its programs and services.</li> </ul>
	Enhance cultivation culture with consistent mechanisms for deepening relationships and expanding organizational base.	<ul style="list-style-type: none"> <li>Added at least 300 new volunteers to HDSA each year through robust outreach and cultivation by staff and volunteer leaders.</li> <li>Hosted two "Thank You Thursday" events each year to express gratitude to HDSA's volunteer community.</li> <li>Introduced Chapter &amp; Affiliate Awards Luncheon at Annual HDSA Convention to recognize exemplary work of HDSA volunteers.</li> <li>Created HDSA Welcome Kit to assist Chapters and Affiliates with onboarding new volunteer leadership.</li> </ul>

<b>VI. Operate in a Fiscally Responsible Manner</b>	Pay all grant obligations on time.	<ul style="list-style-type: none"> <li>Managed revenue and expenses to strengthen cash position and thereby ensure timely payments to all HDSA grants and vendor obligations.</li> <li>Consolidated Chapter banking to maintain more timely cash flow.</li> </ul>
	Establish reserve of at least six months operating funds.	<ul style="list-style-type: none"> <li>Established Board Reserve Policy.</li> <li>Made annual contributions to the HDSA Operating Reserve account. As of December 31, 2016 HDSA maintains more than three months of operating funds in reserve. Efforts to increase this resource continue.</li> </ul>
	Enhance transparency of corporate culture with active engagement of community.	<ul style="list-style-type: none"> <li>Implemented Conflict of Interest and Whistleblower Policies. Updated and maintained ethics policy and related paperwork.</li> <li>Established internal and external communications systems to facilitate information sharing and trust-built relationships.</li> </ul>
	Maintain or exceed 75 percent threshold in mission/admin funding ratio.	<ul style="list-style-type: none"> <li>Exceeded mission/admin threshold beginning in 2014. Current ratio is 76/24.</li> <li>Conducted ongoing education with staff and volunteers regarding "cost to raise a dollar" and the importance of expense management.</li> <li>Implemented quarterly system of financial performance review.</li> </ul>
<b>VII. Increase Revenue to Further Support the Mission Work of the Society</b>	Increase overall revenue by 5 percent annually.	<ul style="list-style-type: none"> <li>Achieved 20 percent increase in overall revenue between 2012 and 2016. Gross revenue was \$8M in 2012, \$8.7M in 2013, \$9.6M in 2014, \$10.1M in 2015 and \$10M in 2016.</li> </ul>
	Utilize new technology to change ways people can give to the Society.	<ul style="list-style-type: none"> <li>Launched the DonorDrive peer-to-peer fundraising system.</li> <li>Upgraded the HDSA.org donor experience.</li> <li>Increased social and traditional media outreach in support of national and local giving efforts.</li> </ul>
	Invest in planned giving program to establish long-term financial stability.	<ul style="list-style-type: none"> <li>Developed annual planned giving campaign, which results in identifying at least 10 new planned gifts each year.</li> </ul>





In the battle against Huntington's disease, no one fights alone.  
**At HDSA, Family Is Everything!**



**Huntington's Disease  
Society of America**  
**Volunteer. Educate. Advocate. Donate.**

**HDSA.org**

**(800)345-HDSA**